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ABSTRACT

This guide notes the value of parent groups for parents of children with disabilities, as they offer parents a place and a means to share information, give and receive emotional support, and work as a team to address common concerns. Typical activities of a parent group are listed, and ways of identifying parent groups that exist nationally and locally are noted. Criteria are outlined for deciding which group or groups would be useful to join, and suggestions are offered for starting a group if no appropriate group exists. These suggestions address: deciding what kind of group to form; deciding whether to affiliate with a larger association; determining leadership and planning the first meeting; handling the first meeting and subsequent meetings; maintaining interest in the group; and serving families who do not speak English. (JDD)

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ED 370 272

A PARENT'S GUIDE

Accessing Parent Groups

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by
Suzanne Ripley

Families with a child who has a disability have special concerns and often need a great deal of information: information about the disability of their child, about school services, therapy, local policies, funding sources, transportation, medical facilities, and much more. Many families find it very useful to join a parent group, where they can meet other families with similar needs. Parent groups can serve many purposes, but primarily they offer parents a place and a means to share information, give and receive emotional support, and work as a team to address common concerns.

There are many different parent groups, and their activities vary, depending on the group's focus and goals. Typical activities may include: providing mutual support and new friendships, distributing information and/or newsletters, creating a family resource center, arranging for speakers on topics of interest, and setting up babysitting co-ops or respite care provision. Many parent groups also allow families the opportunity to speak in a unified voice to express the needs and goals of a special interest group not often well represented in the school and community.

An important function of nearly all parent groups is to introduce families to others like themselves, who can provide much needed information and emotional support. When families with similar concerns meet, there is a sense of community, of understanding; you create a place where you can laugh about the same things, where you can discuss the same problems, where you can help each other. Where else can a parent find out which local dentists are good with children who don't sit still, where to buy specialized clothes, toys, or equipment, how to help a teenager find a summer or after-school job, or how to fill out a social security application?

This Parent's Guide will help you identify the parent groups that exist nationally and in your state and community. It will also help you decide which group or groups would be useful to you in meeting your family's needs and concerns. If no such group exists in your community, this Guide provides many suggestions on how to start your own group.

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Q: ***What are parent groups?***

A: Parent groups are, very basically, a group of parents (or grandparents, aunts and uncles, siblings, foster parents - anyone who is raising this child), primary caretakers, and sometimes other family members who are concerned with disability issues. Some parent groups also include members who are not parents of children with disabilities, such as educators, medical professionals, social services providers, policymakers, and others interested in disability issues. For the purposes of this discussion, the term *parent group* will be used for all groups serving the needs of families of someone with a disability, however diverse their membership may be.

Q: ***What sort of help can parents really offer each other?***

A: There are many ways in which parents, as a group, can help each other. For example, parent groups can provide parents with information on medical or educational services, programs, and other resources available within the community, county, state, or nation. The group can invite speakers to present information on a wide variety of topics at their meetings, or produce a newsletter concerning local services, events, school policy, and state policy. This information is invaluable for "new families" who have just learned of their child's disability, and continues to be useful to families as their needs change through the years.

Within the group, parents can also be open about their fears and concerns. There is a great benefit in learning that there are other families going through the same kinds of situations. Families join parent groups to end the sense of isolation their unique situation can create. Often, families in atypical situations find that traditional sources of help are unable to understand their particular needs or to help them solve problems. By expressing their concerns and problems to other parents, families can get reactions and advice from others who may have experienced similar situations or needs. They can share the daily coping techniques that help keep families together, as well as exchange tips that can make life run more smoothly. Parents can help each other to renew their spirit, determination, and enthusiasm for life. Being able to discuss concerns with others in a similar situation can bring about realistic, pragmatic solutions and is often exactly the support families need.

Parent groups also serve other important needs and offer several advantages. For example, as a group, parents can form a united voice like any other special interest group. In this united voice, they can present their concerns to school administrators and community leaders.

Q: ***What kind of groups are there?***

A: Parent groups vary on the basis of what binds them together. There are groups of parents whose children all have the same disability. There are groups whose members are all involved in the same school or same program in a school. There are groups whose members all live in the same geographic area or who all want to learn more about the special education process and the rights of their children. Parent groups are also formed based upon the specific goals members would like to accomplish. In general, the goals of parent groups are to obtain direct services for children, mutual support, training, advocacy, and communication.

For example, a group may be formed to fill gaps in services. A parent group may establish a child care program for young children with disabilities or open a group home for young adults seeking more independence. Organizations like Parent-to-Parent (this group has different names in different localities) are useful for parents who are looking for understanding and practical ideas about raising a child with a disability. Such groups connect parents with another family whose child also has a disability. Groups whose focus is advocacy organize families to help ensure a free appropriate public education and equal opportunities for children and youth with disabilities.

Many groups provide parent training that can help parents expand their skills in raising a child with a disability. This training may be in such areas as: understanding the special education system; behavior management; self-help skills (such as toilet training or mobility); working with medical experts; identifying and accessing community services; being your own case manager; and/or learning to access and use assistive technology effectively.

Disability groups are formed to represent the interests and concerns of a specific disability, such as United Cerebral Palsy, Spina Bifida Association, Children with Attention Deficit Disorder, Tourette Syndrome Association, and many more. There are groups representing several disabilities, such as the Alliance for Genetic Support Groups, Little People of America, or Federation of Families for Children's Mental Health. There are literally hundreds of such groups, and NICHCY can assist you in identifying them if you can't find what you're looking for locally. Many disability groups have national offices with state and local affiliates, but not all of them do. Smaller groups may have only a few offices or just one.

Some groups have local, state, regional, and/or national offices with sizable membership lists. Some groups may have as few as three members, but this can still be a workable group. There are groups that are run entirely by volunteers and have no income other than possible membership dues. There are local groups that have applied for and received federal, state, or private funding to help pay for staff time, training, development of materials, printing, mailing, and maintaining a post office box or office.

There are large organizations with a full staff of paid workers and budgets that allow for national publications and annual conferences. However, it is not size that determines a group's effectiveness. All groups can play an essential role in providing information and family support and in addressing issues in a collective voice.

Q: ***How do I find out about groups in my area?***

A: First look over the attached NICHCY *State Resource Sheet*. State parent groups will be listed there and can refer you to groups in or near your community. (If you don't have a *State Resource Sheet*, or if you don't find the information you need, contact NICHCY at 1-800-999-5599 and ask for one.) If a group exists in your area, contact it for more information about its membership, goals, services, and meeting times.

You can also contact a variety of other organizations and ask for information about and referral to local parent groups. For example:

- Talk to the special education staff at local schools (both public and private) and preschool and early intervention program staff.
- Talk to social service departments at children's hospitals.
- Talk to vocational rehabilitation counselors and the staff at independent living centers or group homes.
- Look in the phone book under either the specific disability or in the yellow pages under Disability Services.

Don't overlook general parent groups in your child's school or in the community. The PTA (or PTSA) usually has a voice in overall school activities. Local advisory boards and commissions may also be actively involved in issues of importance to your family.

You may find groups which have been established to meet the needs of children with a disability different from your child's disability. However, if this group is concerned with similar issues, it may still be of great use to your family. For example, if your child has mobility difficulties due to a head injury, a group focused on spina bifida might meet your needs, too. Even though the disability is different, the members of the spina bifida group are also concerned about mobility, accessibility, inclusion in school and community programs, and socialization opportunities for their children. They may have speakers talk about IEP development, related services, accessible playgrounds, public transportation, and the like, which are also of interest to your family. It is what a group *does* that is important, not what it may be called.

When you talk to any organization, be sure to ask for the names of other organizations concerned about similar issues. They tend to know each other and can be excellent sources of referral.

Q: ***Should I join one of these groups?***

A: When considering membership in one or more parent/disability groups, it is helpful to review your personal needs. Are you looking for moral support or advocacy training? Do you want to get to know other families who have a child like yours? Do you need a course in sign language or a play group for your three-year-old? Are you interested in hearing speakers on special education and disability topics? Are you interested in becoming involved in local decision-making processes for school and disability issues? Would you like to receive a newsletter on disability topics?

The answers to these questions may help you decide which, if any, group you should join. You may need to join only one group (such as the local chapter of a national group such as United

Cerebral Palsy Association or The Arc) to get all the information you need. Or you may need to join more than one group, if you have more than one need or interest. For example, you might wish to join a national parent group and a local preschool parent group. The national parent group may provide you with a newsletter concerning local, state, and national issues. The preschool parent group, on the other hand, may have established a child care co-op and hold birthday parties for each of the children. The goals of these two groups are different, but together they may meet the variety of needs you have identified for your family.

Ask yourself, what kind of a "joiner" are you? Are you more comfortable with formal organizations, or do you prefer less structure? Consider the types of groups around you, and decide where you would feel most comfortable. In the process of exploring parent organizations, remember that you can always attend one or two meetings before agreeing to join. You can attend meetings of groups now and again without formally joining. If you are interested in joining but can't afford the dues, most groups can offer reduced fee memberships or free membership to those who need it. These are all people who can understand unique situations; talk to them about any special arrangements you might need to participate. Also remember that sometimes the best way to get involved with a new group of people is to volunteer to take a role in some activity. By being a participant, you will get to know other members and learn more about the goals and functions of the organization.

Q: ***What if there isn't a group in the area that meets my family's needs?***

A: Many times there is no local group that meets your family's needs. While it may always be worthwhile to join a far-away group to get its newsletter or other information by mail, you may still want to have a group of local people within your community to address the needs you have identified. When the need for a group is identified and there are people who want to see such a group in their area, then it's time to get together and start your own organization. This takes work, but it can certainly be done.

Q: ***How do we decide what kind of group to form?***

A: Start by answering these questions:

- What is the primary purpose of this group?
- What other purposes are there?
- What schools, disabilities, age groups, and geographical areas would you cover?
- Who would join this group?
- How will you communicate with or reach these people?
- What is the underlying philosophy of the members?
- What are your goals for this year? Can you list them in order of importance?
- When do you want to meet?
- How often do you want to meet?
- Where do you want to meet?
- Who will lead the meetings?
- Will you need to raise any money, charge dues, or solicit contributions?

In answering these questions, you may think of additional questions, but this list should certainly get you started.

Q: ***How do we start a group?***

A: There are basically two ways for families to start a parent group. You can either affiliate with an existing organization — that is, become a local chapter of a larger association — or you can start a new group.

Q: ***How do we affiliate — and with which group?***

A: Once you have answered the questions above, you should be able to match your group's goals and needs with existing organizations. For example, if your group's goals are to provide information about the special education process to parents and offer training on topics such as writing effective IEPs, then you might want to affiliate with a Parent Training and Information Center. Parent Training and Information Centers, or PTIs, exist in every state under a variety of names. This information is on the NICHCY *State Resource Sheet*. PTIs are federally funded and offer parent/family training in special education issues, as well as a variety of other services in each state, including information and referral to state resources, newsletters, advocacy services, conferences, and technical assistance to other groups.

If you have identified your group's goals as providing mutual support by getting families together to talk, then you might find it beneficial to affiliate with Parent-to-Parent. Perhaps your members all have children with the same handicapping condition; in this case, you can affiliate with a national disability association that matches your needs, such as the Learning Disability Association. (Remember, it's useful to think in terms of your child's needs, rather than the specific disability label he or she has been given.)

To identify existing organizations in the state or nation, you would follow the steps outlined on pages 3 and 4. Use the NICHCY *State Resource Sheet*, contact a variety of organizations such as social services departments or people such as the special education staff at local schools, ask the PTI in your state, or look in the phone book under the specific disability or under Disability Services or a similar name (often listed in the phone book in the pages devoted to state and local government).

When you have found a group whose goals and activities are similar to what you'd like to do, contact the group and ask how you would go about affiliating with it. If this group is itself a state or local affiliate of a national organization, ask how you would join with the national office. Talk to representatives of the group about assistance they can offer in setting up your group, in getting subscriptions to relevant publications, about possible speakers and/or local experts, and about other related resources in your area. This is your first networking activity.

Q: ***What if we decide not to affiliate?***

A: Even if your search does not result in a decision to affiliate with an existing organization, it will be useful to have contacts in the disability field with whom you can network. Any established

organization, regardless of differing goals, members, or needs, may have people who can help you organize your group. For example, the Parent Training and Information Center is usually an excellent source of assistance in establishing a disability group. In the same way, any specific disability group will in many ways be structured like other disability groups. You can model your organization after others and profit from their experience.

Similarly, there is no need to duplicate work that has already been done. Another group's information on such topics as disability issues, school policy, state and federal legislation, recreation, summer camps, technology, or parent/professional relations may be useful to your group. Make use of information packages, training materials, and newsletters of interest to your membership, so you can concentrate your resources on those unique, unmet needs you have identified.

You may be forming a small and informal group. If, for example, seven families have decided to meet in their homes, then no formal organization may be needed. You may decide to start a small group which meets informally, has no dues, does not choose officers, and needs no office or post office box. Your group may be successful and small, or it may grow and change its organizational structure.

Q: ***What do we need to do to start a new group?***

A: Once you have considered these questions and talked to others about your group, its goals, and your ideas for issues to address, it's time to actually get started. Here are some general guidelines. Again, you may add any number of additional activities of your own or tailor these suggestions to meet your needs.

- *Determine leadership.* Who will conduct the first meeting? Will you have officers, will you elect a leader, appoint a leader, and get group approval, or elect several officers?

- *Develop an agenda for the first meeting.* You may want to start informally and offer participants a chance to get together to talk or you may want to devote the first meeting to organizational issues. Do you want to invite a guest speaker, show a video, or combine the meeting with a social event? Be sure the agenda is specific, goal-oriented,and short enough that you can comfortably get through all items listed.

- *Arrange for the place of the meeting.* Pick a convenient location that can comfortably hold the maximum number of people you expect to attend. This does not have to be a permanent meeting place, but pick some place easy to find. Be sure this place is accessible to individuals with disabilities; set a good example!

- *Invite guests to the meeting.* Do you want to control who is coming to this meeting or open it up to the public by advertising? You may wish to post notices in places like schools, doctors' offices, libraries, the recreation center, or other locations where your prospective members might see them. The local newspaper may have a section that announces local meetings; call the paper and find out how to access this.

Q: ***How should the first meeting be handled?***

A: Here are some suggestions to help your first meeting be a success.

- Get there early and be sure everything is set up as you want it.
- Be sure to put signs at the door, if needed, directing people to the meeting room.
- Have a guest list for people to sign as they arrive. It is always helpful to have a mailing list of potential members. Even if all participants were invited, you may want to get phone numbers or other information. You might want to add one or two identifiers to this list, such as age of child, school child attends, disability of child, or whatever information may be useful in selecting future activities. Be sure guests understand that they are not signing up to be members or volunteering to do anything; this is an information list only.
- Provide name tags. Guests may not know each other. There are many ways to personalize the tags. Guests could be asked to include information about their child or occupation on the tag. For example, a name tag might read, "Lucy Jones, Tom's mom at T.J." or "Betty Smith, 2nd grade teacher at Hillwood."

When all guests have arrived and you're ready to officially begin the meeting, you might find these suggestions helpful.

- If the audience is of an appropriate size, you may want to take a few minutes to have each person give his/her name, age of child, disability of child, and/or school child attends. Professionals would introduce themselves by giving their name, profession, and school.
- Introduce the leaders of the group or candidates for officers and any community leaders or school officials in attendance.
- Go through the items on your agenda. Don't rush, but keep the meeting moving.
- Set a time and place for the next meeting, and identify possible topics.
- Allow time for socializing and discussion. It's important for members to be able to talk to one another; it's also important not to let this aspect "take over" the meeting, if other items are on the agenda.
- End on time.

Q: ***What should happen after the first meeting?***

A: It's a good idea to send a notice to all those who signed your guest list and let them know you're glad they came. In this letter, you may wish to:

- Give some information on the kind of people who were there, based on the information you collected. For example, you might say that 80% of those attending were parents, over half of their children are under age 8, that most of the children are identified as developmentally delayed or mildly mentally retarded, and that the professionals who attended are all special education teachers at the elementary level.

- Reiterate any decisions that were reached at the meeting, certainly the name of the group, its officers, and the time and place of the next meeting.

- Describe any nominations or elections that are planned.

- Make requests for any needed help. Be specific about what is needed and how much time is involved.

- Provide a means for those who attended to make suggestions and recommend future agenda items.

- Be sure to let people know how to get in touch with you and other leaders.

Q: ***What about future meetings and activities?***

A: Be sure to communicate clearly with your membership. Ask from time to time whether members want to change the meeting place or time. Also ask about issues of concern to your members and for their ideas for speakers or topics of discussion. Encourage members to share opinions and ideas and to ask for information when they are in doubt about whatever is being discussed. Remember to debate the issues, not the persons who present them.

As your group becomes more established, there may be other questions to consider. Many possible questions are listed below. Although not all will be relevant to your group, this list may help the group decide upon future activities or directions.

What are your group's long-term goals?
What do your members want to learn more about?
Do you want to offer or participate in training programs?
Who will arrange for speakers or topics for the meetings?
Who will contact members and advertise the meetings?
Do you want people to be able to reach your group by phone?
Whose number will they call?
Do you need to provide child care at the meetings?

Who will do this or arrange it?
Will you provide refreshments at the meetings?
How will you pay for this?
Do you want to produce and send out a newsletter?
Who will write it? Type it? Mail it?
How will you pay for the newsletter and postage?
Will this work be done on a volunteer basis, or will someone need to be hired?
How much money do you think you'll need to carry out your plans?
Do you plan to raise money and/or apply for funds?
Will you need to make this a formal organization? Will you need to write by-laws?
Do you need to apply to the IRS for tax exempt status? Do you need an auditor?
Do you have someone with experience in organizing nonprofit groups to help formalize your group?

Q: ***What if only a few close people show up for the meeting?***

A: Don't confuse interest or effectiveness with numbers. Some topics only attract a small audience, but they may be of great interest and importance to those people. In general, more people will say they can attend than actually get there; there are many difficulties that may prevent people from attending, including childcare, illness, transportation, schedule conflicts, weather, or just plain exhaustion. Large attendance is not the key to success.

However, if attendance is regularly lower than the membership, there are several explanations. Some people join groups for reasons other than attending all the meetings. They may join to receive a newsletter, to be part of a group that is working for the benefit of their child, or to attend only one or two meetings of special interest, or they may simply not have the energy to go back out at night even though they are impressed with the mission and work of the group.

You also should be careful to avoid scheduling meetings at busy times; consider experimenting with a variety of times and days, interspersing informational meetings with more social gatherings, and regularly surveying your membership for suggestions on meeting times, locations, and topics.

Q: ***How do we keep up interest?***

A: A group is made up of members who may have distinct ideas of what's interesting, needed, or convenient. Be sure to keep communications open, and try to elicit ideas and participation from all members. A group managed entirely by a few members runs the risk of not only overworking their leaders but also of having no pool of upcoming leaders to carry on the work. Next year's success or even the continuation of your group will depend upon identifying new leaders and new volunteers and upon maintaining a sense of interest and commitment.

To keep your leaders from burning out and to provide opportunities for a new leadership, you may want to:

- Form committees to address different activities;
- Share and delegate the tasks to be performed;
- Have as many people actively involved as possible; and
- Have one-time-only activities that members can choose from. Many people cannot commit themselves to one more activity, but will certainly help out for an hour or two.

It is also helpful to discuss your mission every year and redirect it, if necessary. Schools change, communities change, your membership may change, and children are certainly always changing. What is important one year may not be a burning issue the next year. Examining the mission of your group can play a critical role in assessing your successes, learning from your mistakes, identifying new goals and needs, redirecting your efforts, and maintaining and renewing members' interest in the group.

Some groups may form to address a specific goal, such as providing an accessible playground or establishing an information center. When this goal is accomplished, the group may choose to disband. That's okay, too.

Be sure to let NICHCY know about your group, so we can be part of the same network. Put us on your mailing list, and we will add your name to ours.

Q: ***What about families who don't speak English?***

A: There may be families in your community who are not fluent in English and who have children with disabilities. They, too, may be interested in the support available from other parents but may not be comfortable in an English-speaking group. In this case, a one-to-one friendship may be very helpful, in terms of both emotional support and information gathering. There are several other possibilities that can be considered, too.

Many people who do not speak English fluently may be able to read English quite well. For these people, newsletters or other publications may be of interest. If you're establishing a parent group or joining an existing group in an area where there are families who speak another language, you may wish to share your information with them. They may be interested in forming a parallel group, using some of the suggestions in this guide. It may be beneficial to all involved to arrange occasionally for translators so that both groups can share ideas and concerns, let each other know the issues being discussed in each group, or attend when special speakers are invited to either group's meeting. You both can also benefit through presenting a united voice in the decisions made in your community.

> For members of your community who would benefit from either joining or forming a Spanish language parent group, this publication will be available in Spanish in September 1993. For a copy of *Accessing Parent Groups* in Spanish, contact NICHCY at 1-800-999-5599.

Additional Resources Available From NICHCY

The following materials are available from NICHCY. They may be helpful to you in gaining a better understanding of the special education process, laws, and how to access services in your area. All of these materials are available free of charge. Information about other NICHCY publications is available by requesting a *Publications List*.

A List of National Resources.

General Information about Disabilities.

Public Agencies Fact Sheet.

A List of National Toll Free Numbers.

State Resource Sheets.

To order, contact NICHCY:

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